Health Promotion & Disease Prevention

Outcomes	Interventions
Young person has a medical home and knows how to contact the MD/clinic	Assess if young person has a "medical home"
Young person has had a primary care health visit it is the most support to the primary care health visit	Provide assistance with finding a primary care physician if does not have "medical home"
within the past year	Encourage yearly health promotion visit to primary care provider
• Immunizations are up-to-date and young person has record	Assess immunization status
	Provide information regarding recommended immunizations and the importance of immunization(s)
 Vision and hearing are assessed if risk factors exist or problems identified, and glasses, hearing aids, or 	Refer to primary care provider or local health department as needed
compensatory strategies are learned and used.	Refer to primary care provider or specialist for vision and hearing assessment and treatment as appropriate
Young person's Ht/Wt ratio does not indicate obesity or malnutrition	Weigh and measure patient at least yearly and plot on growth chart
Growth follows normal curve	
• Young person demonstrates good nutrition in food choices (three meals daily, low fat, low sugar, moderate salt, 2-4 fruits, 3-5 vegetables, 6-11 whole	Teach how to choose healthy foods including fruits and vegetables
grains)	Assess calcium intake and risk factors for calcium depletion (immobility, medications, etc.)
 Young person has adequate intake of calcium to prevent early onset osteoporosis 	Encourage adequate calcium intake (foods and/or supplements)
	Encourage family to eat some meals together
 Young person has not experienced an unexpected weight loss >10% of previous body weight 	Assess for excessive dieting, self-induced emesis, use of laxatives
	Refer to PCP if signs and symptoms of anorexia or bulimia

Young person's risk for developing hyperlipidemia Assess BP yearly on children who are obese, have or adult coronary heart disease is assessed and compromised renal function or positive family prevention/treatment measures are implemented history Provide teaching regarding the prevention of coronary heart disease Refer to PCP for increased BP, BMI > 95th percentile or positive family history of heart disease Young person does not have severe, untreated acne Assess young person's concern related to skin problems Provide teaching related to special skin care needed during adolescence Refer to PCP if adolescent is concerned or there is noticeable papular/pustular or cystic acne Young person engages in appropriate health promoting behaviors such as: Assess health promotion activities with direct questions to the young person moderate exercise 5 of 7 days per week, 30 minutes or more per occasion Provide teaching as appropriate to interest and need limited TV viewing, video games, etc. (<2 hours daily) Encourage both aerobic exercise and strength training adequate sleep or rest consistent use of car seat belt or WC Refer to physical and occupational therapy to assess restraint exercise needs and develop program no exposure to passive smoke uses sunscreen and avoids sun exposure Assess sleep patterns knows how to swim wears helmet when cycling and other Provide teaching on the importance use of seat belts protective gear as appropriate for activity and protective equipment uses work-related safety gear and follows safe work procedures

 Young person has good oral hygiene, no untreated dental caries Young person brushes and flosses daily Sees the dentist yearly and receives preventive and restorative care. 	 Assess dental hygiene Teach how to brush and floss teeth as needed Encourage regular dental check-ups; refer to dentist as needed Assist in finding resources to pay for dental care as needed
Young person asks questions about physical and emotional changes of puberty and how condition affects puberty.	 Assess level of understanding and readiness to learn Provide privacy and protect confidentiality Provide information related to puberty as appropriate to developmental age
 Young person conducts breast or testicular self-exam monthly Young person understands potential effect of disability on sexual functioning and reproduction 	 Answer questions within the context of the young person's family values and culture Provide verbal and written information regarding breast or testicular self-exam Assess level of understanding and interest Provide with appropriate information
 Young person understands safe ways to prevent pregnancy and contracting sexually transmitted diseases, including HIV/AIDS If sexually active, young person receives health care for birth control, STD evaluation, and education All pregnancies are intended 	 Refer to geneticist, gynecologist or urologist as needed Encourage abstinence until emotionally mature in a committed relationship Provide with written information about pregnancy, safe sex, contraception, STD's and HIV as appropriate to situation Refer to PCP or gynecologist/urologist for evaluation and treatment Ensure primary physician is identified on medical
Young person's specialty care is coordinated with primary care physician	 Ensure primary physician is identified on medical records release of information Provide the young person with the opportunity to sign or co-sign release of information form Coordinate care with PCP

Health Problem Management

Outcomes	Interventions
Young person interacts directly with physicians, nurses, therapists	Direct questions to young person rather than parents
	Provide privacy and time without parents
 Young person is knowledgeable about health condition/disability and can describe condition to others Young person demonstrates competence in health problem management skills such as: treatments medications (including side effects, how meds interact with food, alcohol, tobacco, other drugs) therapy exercise orthopedic appliance and wheel chairs (including minor repairs, who and how to contact vendor and payment mechanisms) latex allergy bowel program bladder program 	 Assess current level of understanding Assess competence with appropriate Health Care Skills Check-List and/or observation Teach young person about health problem(s) and how to manage care Provide with appropriate information including internet sites relating to disability Complete appropriate health problem management plan/worksheets and include in transition workbook
prevention of skin breakdown	
Young person demonstrates health practices which will prevent secondary disabilities such as:	Assess risk status for secondary disabilities
 obesity or undernutrition contractures skin problems constipation urinary tract infections 	 Teach young person about risk of secondary disabilities associated with health condition and cues to early identification Teach to monitor for secondary disabilities
The young person is free of secondary disabilities	Individualize prevention and monitoring activities and include in transition workbook
Young person does not have preventable hospitalizations.	

Young person identifies signs and symptoms which require prompt medical assessment or intervention	 Assess level of understanding Teach young person to recognize signs and symptoms which require prompt medical assessment and intervention such as: infection problems breathing skin break down high fever allergic reactions
 Young person has an appropriate plan for medical emergencies States signs and symptoms of medical emergencies Can activate EMS or another community-based emergency system 	 Teach signs and symptoms of medical emergencies related to health condition Teach how to activate EMS
 Young person wears medi-alert ID as appropriate: latex allergy drug allergies food or environmental allergy diabetes, etc. 	 Assess if medical alert for allergies or life threatening condition is needed Provide information about how to obtain medical alert ID Develop emergency care plan and include in transition workbook
 Young person knows how to access needed equipment, supplies, therapies and other services Knows how to work with and through the PCP or managed care organization or other funding resources as appropriate 	 Assess for need for additional equipment, supplies, therapies or technology based on age/developmental or functional changes/states Explore funding source for equipment, supplies, therapies and other needed services
	 Obtain prior authorization with third party payors or managed care organization Facilitate referrals to public and private agencies for equipment, supplies, therapies and services Coordinate care with other providers

Young person has payment source for health care (private insurance, Medicaid, or other resource) and carries information card.	 Assess current third party resource Assess for changes that may occur at age 18 related to SSI or Medicaid
	 Assess age limitations on parent insurance and implications for young person Help young person and family plan for transition from family to individual insurance.
 Young person can access and use third party payer Understands prior authorization process Understands gatekeeper concept Understands how to use third party case management Knows what is covered and not covered and necessary co-payments Knows how to submit bills for payment and follow up disputes 	 Provide information on SSI and Medicaid Assess knowledge of how to work with third-party payors Teach how to work with third party gatekeepers or case management systems Teach how to advocate for self with third party resources
 Young person has access to adult primary and specialty health care providers identifies need for adult primary and specialty health care providers has a plan for transition to adult healthcare providers at ages 18 or 21 has identified adult providers records transferred to adult providers first appointments made first visit completed 	 Assess access to adult health care Provide young person with names of medical family practice and specialists in local area or resources for identifying appropriate specialists as needed Follow-up to ensure that appropriate adult specialty care has been found Send records to adult health care provider
 Young person has completed pediatric care and has needed: records prescriptions equipment prosthetics orthotics therapies Knows how to contact providers for these services and products in the adult system 	 Assess for need for prescriptions, prosthetics, orthotics, equipment Facilitate young person receiving what is needed prior to transition from pediatric to adult health care system Provide copy of discharge summary at last visit

Development & Self-Care

Outcomes	Interventions
Young person is able to communicate needs, concerns and priorities and advocate for self	Ask young person to identify needs, concerns and priorities
	Assess capacity for self-advocacy
Young person has independent mobility or can instruct attendant	Assess mobility status and needs
instruct attendant	Optimize mobility at home, school and the community
	Encourage exercise and recreational opportunities which promote mobility
Young person demonstrates competence in self-care	Assess level of competence in ADLs at least yearly
skills and/or has an appropriate long-range goal for developing a plan for self-care skills such as: • bathing • dressing • grooming • toileting (clean intermittent catheterization or bowel program) • inspecting skin • transferring to toilet, tub, car • mobility at home, school, community • interviewing, hiring, instructing, evaluating and terminating attendant	Encourage family and young person to make self- care a top priority
	Increase levels of responsibility for home management and chores
	Discuss with parents developmental issues surrounding the need for privacy during adolescent years and the importance of self-care
	Refer to PT/OT for evaluation and intervention as needed
	Evaluate need for inpatient habilitative admission for self-care training
	Coordinate pre-admission and discharge planning related to in-patient habilitation admission or summer camp programs

- Young person demonstrates competence and/or has an appropriate plan to develop home management skills such as:
 - fixing/cooking food, snacks, and meals
 - shopping for groceries, clothes, and other supplies/needs
 - housekeeping
 - laundry and clothing care
 - money management, budgeting, and banking
 - using phone

- Assess level of competence in home management skills
- Encourage family and young person to make learning home management skills a priority
- Encourage independence in all home management skills
- Provide opportunities for money management
- Allow young person to experience consequences of both good and poor decisions
- Evaluate the need for an inpatient admission to learn home management skills
- Coordinate pre-admission and discharge planning related to in-patient habilitation admissions or summer camp
- Young person demonstrates competence in and/or has an appropriate plan to develop community living skills such as:
 - driving and/or use of public transportation
 - housing finding and modifying for accessibility
 - accessing and using community resources
 - income maintenance (job or SSI)
 - protection against crime/exploitation
 - recreation
 - navigating streets, reading maps
 - communication skills to interact with peers, authority figures, and community members

- Assess level of competence in community living skills
- Provide information related to appropriate community resources
- Refer to VR for vehicle modifications/drivers training
- Refer to independent living organizations, support groups and advocacy organizations as needed to achieve independent community living goals

- Young person states what accommodations are needed in home, school and community
- Architectural barriers which limit independence are removed
- Young person and family understand rights and responsibilities under the ADA
- Assess home accessibility and architectural barriers
- Assess vehicle and school accessibility
- Refer to independent living centers for assistance with accessibility issues
- Provide information about ADA

Self-Perception

Outcomes	Interventions
Young person exhibits planning and decision making appropriate to developmental age	 Assess planning and decision making skills Problem solve directly with the young person
	Involve the young person in planning and making decisions to the greatest extent possible
	 Encourage taking responsibility for positive and negative outcomes of decisions
Young person can advocate for self	Assess advocacy skills
	Encourage young person to advocate for their needs at school and with health care personnel
 Young person reports having a positive self-concept: can identify positive attributes 	Assess self-concept by asking "What do you like most about yourself?" "What do you do well?"
 can identify special talents reports that "my life has a purpose" has fun in health-promoting ways 	Refer young people with low self-esteem to appropriate community resources as appropriate
 Young person has a plan for his/her future and is optimistic about the future 	Ask "What do you think you will do when you graduate from high school?"
	Encourage young person to take concrete steps to make their future something positive
	Relate present activities to the future
	Provide the young person with support and encouragement about the future

Coping & Stress

Outcomes	Interventions
 Young person can identify what causes stress in his/her life Young person participates in effective stress reduction activities such as: music meditation/worship exercise/sports/recreation hobbies and leisure activities fun with friends and family 	 Assess for perceived level of stress Assess effectiveness of stress reduction and coping strategies Provide information on stress reduction activities as appropriate Refer to appropriate resources if stress-related problems
 Young person does NOT engage in high risk behaviors such as: smoking/chewing drinking using illicit substances unsafe sexual practices thrill-seeking when driving riding or driving with someone under the influence of alcohol/drugs physical fighting carrying a weapon 	 Teach prevention strategies to young people and families Assess if using high risk behaviors as "coping" mechanisms Provide information and alternatives Refer to appropriate community resources
 Young person does NOT exhibit signs and symptoms of severe anxiety or depression such as: report being sad, unhappy, or depressed declining school grades lack of interest in school or peer group activities excessive weight loss or gain excessive sleep or insomnia risk taking behaviors such as drugs, alcohol, sex, eating disorders suicidal thoughts, plans or attempts Young person who exhibits symptoms of mental health problems receives appropriate referral and treatment 	 Assess for signs and symptoms of high levels of stress anxiety or depression either by history or written self-assessment Refer to psychologist or local health and social services if signs/symptoms of depression are noted
Young person does not report or demonstrate symptoms of emotional, physical or sexual abuse	 Assess for potential or actual abuse Provide information on prevention strategies Refer to family and community services if risk factors present or abuse reported

Family & Community Support

Outcomes	Interventions
Young person receives consistent encouragement and support from family and/or friends and/or community members	Assess family interaction patterns
	Refer to appropriate community resources if young person lacks family support
Young person can discuss future plans and concerns with caretaker and one other non-parental adult	Encourage caretaker to be honest and direct in communication
	Encourage young person and family to complete family communication worksheets in transition workbooks
Young person is included in family decisions and given useful home and community roles	Ask young person what they like and don't like about their daily routine and activities – make changes based on their ideas and input
	Include young person in meaningful household responsibilities. Be clear in expectations and standards
	Encourage independence and self-direction in completing household responsibilities
	Encourage community service through church, school, and/or family-supported activities
Family has clear rules and consequences and monitors the young person's activities and friends	• Assess parenting approach. Are there rules, expectations and boundaries? Are they equal for all children in the family?
Young person respects parental limits	Encourage caretakers to be consistent and firm about expectations and boundaries
Young person has a sense of community belonging and responsibility	Assess young person's experience of community
 Young person has spectator and audience member skills; can order, dine, and tip in restaurants Young person identifies acceptable dress for a 	Encourage community involvement and volunteer activities as appropriate
 variety of situations Young person can arrange social activities Young person has registered to vote and/or for military selective service, if appropriate 	Help young person discover ways to help others

School & Work

	Outcomes	Interventions
•	Young person and family express satisfaction with school program, student attendance and performance	 Assess school placement, program, attendance and performance Encourage school attendance and counsel against
•	Young person attends school regularly	"homebound" programming stressing benefits of social interactions with peers
•	Young person has effective study skills	Encourage young person to set short-term and long- terms educational goals.
•	Young person is in a program appropriate for academic skills and social integration	term educational goalsAssess level of motivation
•	Young person is motivated to do well in school	 Teach caretaker the importance of child doing his/her best in school
•	Young person does homework when assigned	 Assess if homework is a priority
•	School accommodates to facilitate health problem management	• Encourage caretaker to create time and space for homework
•	Young person receives needed therapy or treatments	 Encourage caretaker to monitor homework completion
•	at school by qualified provider Young person completes high school or equivalent	 Encourage caretaker to make homework the young person's responsibility to the greatest extent possible
		Assess if accommodations made
		• Assess if nurses and therapists are available to meet health needs
•	Young person has up-to-date IEP which addresses health/disability needs and concerns and career	Obtain copy of IEP for medical record
	guidance	 Encourage young person to participate in IEP development
•	Young person and family participate in the development of the IEP	 Participate in developing the health component of the IEP
•	Young person and family participate in the development of the Individualized Transition Plan	Teach self-advocacy
	T	 Provide with information relating to educational rights under IDEA and section 504 of the Rehabilitation Act

- An Individualized Transition Plan (ITP) is developed which supports the young person's and family's vision for the future
- Young person actively engages in personal futures planning
- Young person can describe personal learning styles, career interests and opportunities
- Young person has a resume and model letter requesting recommendations.
- Young person has a plan for post secondary education or job training which includes:
 - Job fairs, junior achievement, Scouts, 4-H, etc
 - Pre SAT/SAT/ACT
 - Knowledge about pay scales and education/experience needed for jobs of interest
 - Selecting a college or post secondary program (interests, geography, abilities, funding, disability supports)
 - meeting admissions criteria
 - completing application process/interviewing
 - funding: scholarships, loans, work/study

- Obtain a copy of the transition plan and evaluate health/disability implications
- Assess if a school to work or transition plan has been established by the school
- Coordinate transition planning with school to ensure health needs are integrated into planning for the future
- Provide young person with handout relating to personal futures planning
- Assess young persons post-secondary or job training plans
- Encourage discussion with high school counselor
- If high school counselor is unavailable, provide with needed information or resources relating to study skills, admissions criteria, funding, etc.
- Develop a plan for post secondary education or job training that matches strengths with career interests
- Refer to college and technical school disability support centers
- Young person is aware of resources and services available through
 - Family and friends
 - School to Work
 - Vocational Rehabilitation
 - other jobs training and placement programs
- Assess level of awareness
- Provide information on vocational rehabilitation school-to-work, and other programs and how those programs can assist the young person (This information is State specific)
- Plan how to best utilize available resources
- Refer as appropriate to health condition, age and financial eligibility
- Coordinate care with the jobs training or placement agency and obtain copy of the agency's plan

- Young person is provided with career guidance and job exploration opportunities
- Young person learns about work world and develops work skills and ethic by:
 - responsibilities at home and chores
 - part-time work/ summer work
 - volunteer work and shadowing workers
 - full-time work
- Young person has developed interpersonal skills necessary to maintain employment
- Young person can advocate for self regarding accommodations needed

- Assess extent of guidance provided by school/family
- Encourage career exploration
- Assess young person's involvement in home responsibilities and work
- Encourage young person and family to find ways to develop work ethic

- Young person understands how to access and use SSI Programs designed to support school-to-work activities (PASS, 1619 A & B, IRWE, Ticket to Work with Medicaid buy-in)
- Young person becomes employed in a position with health benefits by age 25
- Assess level of understanding of SSI and other programs of support to people with disabilities
- Provide young person with information on work incentive programs (<u>www.ssa.gov/work/workincentives.htm</u>) and contact Centers for Independent Living
- Provide information as appropriate
- As appropriate, caretaker recognizes the importance of establishing guardianship and a will or trust for the young person with a severe cognitive disability
- Assess level of understanding
- Provide appropriate information
- Refer to legal services as appropriate



MCHB Healthy and Ready To Work Projects



KY Commission for Children with Special Health Care Needs KY TEACH Project

Shriners Hospitals for Children

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MCHB Healthy & Ready to Work Policy Briefs available at: www.mchbhrtw.org

- Key Transition Issues for Youth with Disabilities and Chronic Health Conditions
- Understanding the 504 Mandate: The Role of State Title V Programs and Health Care Providers
- State Title V Rehabilitation Services: The Federal Law & How States Implement It.
- Sexuality Issues for Youth with Disabilities and Chronic Health Conditions
- Youth with Disabilities in Transition: Health Insurance Options and Obstacles.

This site offers links to a variety of transition resources in addition to describing the Maternal and Child Health Bureau's Healthy and Ready to Work Network.

Other Web Sites:

Academy for Educational Development: www.aed.org Transition information and assistance in developing programs

Access America for People with Disabilities: http://www.disAbility.gov

July 26, 2000, marked the 10th anniversary of the signing of the Americans with Disabilities Act. In celebration of this milestone, the Presidential Task Force on Employment of Adults with Disabilities (PTFEAD) created this site, www.disAbility.gov, to provide one-stop online access to resources, services, and information available throughout the Federal government.

The Adolescent Health Transition Project: http://depts.washington.edu/healthtr/
Designed to help smooth the transition from pediatric to adult health care for adolescents with special health care needs. This site is a resource for information, materials, and links to other people with an interest in health transition issues.

American Academy of Pediatrics: http://www.aap.org

adolescents

Education and IDEA: http://www.ed.gov

Family Voices: http://familyvoices.org

GAPS: http://www.ama-assn.org/ama/pub/category/2279.html Describes recommendations for medical care

for adolescents

http://www.health.gov This is a portal to the web sites of a number of multi-agency health initiatives and activities of the U.S. Department of Health and Human Services and other Federal Departments. The site is coordinated by the Office of Disease Prevention and Health Promotion, Office of Public Health and Science, Office of the Secretary, U.S. Department of Health and Human Services.

Healthfinder: http://www.healthfinder.gov Guide to a vast variety of health information

Internet Resources for Special Children: http://www.irsc.org

Department of Labor Information: http://www.dol.gov

National Center on Self-Determination: http://www.self-determination.org/ The self-determination movement

was founded on four basic American principles: Freedom, authority, support, and responsibility.

PACER: www.pacer.org PACER Center has been a leader in transition services for years.

President's Committee on Employment of People with Disability: www.pcepd.gov

Scholarship information: http://www.regis.edu/grants/scholar.htm Includes information specifically for people

with disabilities.

Shriners Hospitals for Children: http://www.shrinershq.org

Social Security Administration: http://www.ssa.gov also

http://www.ssa.gov/work/ResourcesToolkit/resourcestoolkit2.html

Ticket to Work: www.hcfa.gov/medicaid/twwiia/twwiiahp.htm

www.wemedia.com Large website with many disability services

www.disabilitycentral.com

www.halftheplanet.com

Web Sites related to Health of Women with Disabilities

<u>www.jik.com</u> June Isaacson Kailes, Disability Policy Analyst: click on Health, Wellness, and Aging with Disability for information and links

www.4woman.gov National Woman's Health Center: Women with Disabilities section

www.bcm.tmc.edu/crowd/ Center for Research on Women with Disabilities

<u>www.fpg.unc.edu/~ncodh</u> Web site for the North Carolina Office of Disability and Health: Many resources on health of women and adolescents with disabilities.

Websites on Recreation for People with Disabilities

www.wowusa.com Winners on Wheels

www.soky.org Special Olympics of Kentucky with links to national and other state Special Olympics.

<u>www.accesstr.com</u> Access to Recreation: Information on adaptive equipment for all kinds of sports and recreation (includes pictures)

http://ncpad.cc.uic.edu National Center on Physical Activity and Disability

Journal Articles: Med Pub can be searched by logging on to www.uky.edu and click on Medical Center, then Library and Information Services, then on Medical Center Library (on the right of the page) and then on Pub Med (in center of text or on left column). This is a free service of the UK Library – you can get abstracts of many articles and some complete articles are on line.

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